

San Bernardino Regional Office

Regional Advisory Committee (RAC)

Minutes

12/11/2021

Location: Virtual Meeting via ZOOM

Posted on https://scdd.ca.gov/sanbernardino/

Members Present

Christina Christenson-Rockwell, Vice Chair
Dustlyne Beavers
Cindy Cox
Eric Aguilar
Kim Risser
Reginald Davis
Violet Arellano, Member-At-Large
Maia Pawooskar, Secretary
Cathy Rosas
*Ernie Saldana

Members Absent

Lanette Hollowell Ronald Allan Carmela Garnica

SCDD Staff

Scarlett VonThenen, Orange County, Office Regional Manager Joe Hernandez, Self-Determination Program Project Manager Alejandra Rivera, Associate Government Program Analyst (AGPA) Carol Nakamura-Robinson, Community Program Specialist II (CPS II)

Meeting called to order at 10:04 am

Quorum established

Approval of Minutes



Voting on the minutes - Maia Pawooskar & Christina Christenson-Rockwell will abstain from voting on 10/09/2021 minutes.

Cindy Cox Motion to Approve the minutes, Dustlyne Beavers 2^{nd's} Motion. Minutes approved.

Welcome Introduction

- Joe Hernandez, Self-Determination Program Project Manager
 - Newly hired, to finalize drafts if modules for Self-Determination. These modules will be disseminated statewide.
 - Intention is to create plain language material and more thorough trainings. To spark interest to those who have not been through orientation for self-determination and might want to further dive into self-determination.
 - Building modules that help you along the way along the process, as opposed to kind of just giving you everything all at once.
 - Will be offered in seven different languages
 - Will be administered virtually and hopefully in person soon.
 - Will not replace the Regional Center trainings but work in cohesion with them. Allowing for more accessible trainings to individuals to get oriented and start on-boarding process. As well as have a better understanding of the program.
 - Background family member and advocate. Started working in the system since providing respite to family member. Multiple years working in day program and work programs.
 - Recently worked with a Statewide Vendor for all Regional Centers in Traditional and in SDP offering Financial Management Services. Been involved with Self-Determination since it's pilot phase.
 - Understands the barriers by talking to individuals in the community.



RAC Meeting Days/Calendar Discussion and Vote

- Time and days, we offer RAC meeting makes it difficult to have members from the community or professionals come a speak at our RAC meetings but are unable to due to weekend times.
 - Cathy Rosas Interested in date change to Weekday.
 - Dustlyne Beavers In favor of moving to Weekday.
 - Suggests 2nd Tuesday of the month
 - Maia Pawooskar Concern moving to Weekday, we need to accommodate working families and daily activities.

- Cindy Cox In favor of moving meeting date
 - Suggests meeting time change 4:00pm 6:00pm to accommodation working individuals, doctors' appointments, or other daily activities.
- Cindy Cox Motions to move RAC meeting date/time to 2nd
 Tuesday of every other month from 4:00pm 6:00pm, Dustlyne Beavers 2^{nd's} Motion. RAC Meeting date/time change passes.

SDP Systems Change Advocacy

Guest Speaker Marty Omoto, CDCAN

- Older sibling a sister with developmental disabilities and was very close to them and age. While attending school with her he saw first how parents raised sister very inclusive in the late 60s early 70s. There was no one to teach my parents on how to raise a child with disabilities and there were no services back then. Saw how she had to deal with life, not only in my own family but in public school special education. She was mistreated and I saw that this and another student saw. Growing up seeing how the same problems happening to other families. This is very personal to me and I owe my advocacy to her. She passed away in 2003 when we were organizing a big protest demonstration against cuts. Her memory and her life are the reason I'm here today.
- Also extended family to a young man 29 years old with down syndrome and on the autism spectrum. Known him since he was seven and his mom died a couple of years ago, she was one of my closest friends. I would promise I would take care of him and I would be there for him and so he lives with me now.
- Statewide advocate for over 25 years.
 - Started writing and organizing writing about information about what was happening at the State Capital. Organizing Statewide meetings that were never done before so that families individuals with disabilities workers could know what's happening in Sacramento.
 - From there helped to create and move change. Before there was the Internet, YouTube or Instagram.
 - Bringing families and people with disabilities to the budget hearings so that we can show them what we look like. To hear our voices that had never been done before.
- The reason why I got involved was because of my sister because her life depended on these services and the State has a responsibility to provide it to her and to my family.
- Served on the on the Statewide Self-Determined Nation Program Work Group.

- The partner of Developmental Disability Services DDS organized in 2013. Coming up with ways of how to implement the program and I think the biggest thing for all of us to get is still in the whole idea is that it needs to be person centered.
 - The idea that it is a system change, but it is about person change or connected to people and the outcomes of those individuals. Self-determination is always about the individual.
 - We must remember that yes, they get services within the system. It is not about the changing the system as much just changing their life individually.
- People are now involved in Self-Determination which is now starting out even though the legislation was passed in 2013 implementation began a few years ago and now it's opened to everyone.
 - There are still barriers and problems of trying to make it work and it is very difficult because there are a lot of new people and I know there can be frustrations and those frustrations could be very hard for families and facilitators.
 - Facilitators are valuable but it's so important that we don't give up and that we work together noticing the problems and we need to then organize together to try to make changes.
 - Do not barrier's we should organize together to try to change that to make it easier for the next person.
 - Self-determination is going to be important because as you start to get involved with this program you are involved in creating change. If it is done right, the person in a meeting will be getting service they had not before.
 - Creating change for others to see, this is why it's so important to face and overcome barriers we can make necessary changes.
 - Committed to helping everyone, contact if there's change that need to happen. One person has one voice and make some changes, but if you really want to make a change that impacts more people or even the State level we need to link together.

Q&A Format

Alejandra Rivera

- Our region concerns Delays in the SDP process. Lengthy time to transition into the SDP program as well as just a lot of little challenges that come across.
 - Example: Clients in traditional services are stuck when entering STP. POS authorizations were sent in and there's a month of gap in the client that

needs critical services. They are not able to access those services not even through traditional services.

- Christina Christenson-Rockwell
 - Another barrier Working with different Regional Centers is there is a huge difference in the way STP transition rules are interpreted.
 - What can be funded and is to be considered an unmet need under traditional.
 - Will allow for an increase in funding but interpreted differently depending on which Regional Center.
 - Some are very cooperative and easy
 - Other Regional Centers that have remained obtuse about the way SDP is supposed to work. They do not seem to be very welcoming to the whole concept of SDP.
 - Have not been able to see value. Partially because now we can meet so many needs through SDP that were not able to in traditional services.

Marty Omoto –

- On several Statewide Work Groups. Developmental Services Task Force and other Statewide level Stakeholder Groups.
- Will raise questions and issues discussed in today's meeting and bring to those groups.
- Will reach out and work with Alejandra with updates.
- Kim Risser
 - How is supported living different than Self-Determination?
- Marty Omoto
 - Supportive Living is its personal care in the home. Which is authorized or you can get in Self-Determination, but you might craft it in a different way than how it's provided in the conventional traditional system. In Self-Determination the person or family who receives services has much more control and decision making.
 - In Supportive Living or even in IHSS, IHSS was designed to be self-directed meaning self-directed by the person who's receiving the services.
 - In theory Supported Living was set up in that same way, were the individual or the family receiving the services has a right help direct.
 - Self-Determination takes it further in which the individual or family can define with those services in the home. Can

hire and fire more control in decision making than what you can do in the conventional system.

Maia Pawooskar

- The question the most issues with the Regional Center is the budget. The budget approval is taking forever that has been the most common observation.
 - Parents have noted that and proposed a notice to the advisory committee. Regional Center has acknowledged because of the current mechanism that they have is small staff that meets once a every month and now I think maybe twice a month or once a week. But if it's only time that the budgets are approved. The process takes forever and some of the things that they have said is because of the POS. The system that they use which is archaic cannot accommodate the new numbers that SDP has. The Regional Center has said it is looking for guidance from DDS or a solution from DDS.

Marty Omoto

- The Development Services Task Force will meet on December 17. The State needs to hold meetings and start helping to solve these problems at the State Level with the Self-Determination Work Group. It still exists but it stopped meeting two years ago.
- There's a need for the work group to help work with the department to solve these problems. The issue of the budget process taking too long. Regional centers of our waiting or believe they need more direction and the other problem is that if you do not provide more direction, meaning the State. Then individuals at Regional Centers may misinterpret the information or the rules in the wrong way and pass on misinformation.
- Without good direction coming from the State misinformation happens or people do not do anything.
- Needs to continuity of care meeting there should be seamless that if you're receiving services in it conventional system you should continue to receive those until Self-Determination starts. There should not be a break in service.

Violet Arellano

 You are saying there is a gap between services with IRC and as you transition to the Self-Determination? The process looks intimidating, if you are looking at the paperwork process just to get IRC going to start Self-Determination. It is intimidating. I think some people will just look at this and ask when I am going to get all this done. Then to hear there are other issues, and delays that is just wrong.

Marty Omoto

 My question to all of you is when a problem like theses occur do you know who where to go to get help? I know the State Council to see if they know the answer or to Regional Center.

Alejandra Rivera

- We receive phone calls from Independent Facilitators that serve our region. They already know who to contact. They have established relationships with some of the managers or people involved in the Self-Determination program. So, they try to trouble shoot some of the challenges.
- We can reach out to the Ombuds person if we keep seeing the same challenges.

Marty Omoto

- Good point the Ombuds person, interim person currently is Katie Hornburger. To contact if the problem keeps occurring.
- Concern is that these problems are being discussed on the local level and no else knows about it. But it is the same problem occurring, and because it does not rise to the State level and someone is documenting it, it keeps happening over and over again.

Maia Pawooskar

- This is what the Statewide Self-Determination Advisory Committee is for. Meeting twice a year, where the Chairman's bring it up to the State level.
 - Statewide SDAC Work group of 6-7 individuals who discusses systemic issues with SD.

Dustlyn Beavers

- Work in 18 Regional Centers over the past 3-years transitioning participants. Has a firsthand look at what works well in a Regional Center around SDP and Regional Centers that a not doing so well.
- Systemic issues bottleneck with on gatekeeper high in the chain of command. They have taken away decision making, and approval authority not directly instructed but implied. That everything must go up to Director of Clients Services.
 - All the Self-Determination plans, budgets, etc. are relying on one person.
- Another concern the Regional Centers desires to create committees for different parts within the budget approval

process. What happens is does not matter how good your Person Center Plan is, or how thorough you are and how detailed your spending plan can be.

- This information goes back to these committees occurs without participant or advocate and you are solely relying on your service coordinator and possibly program manager to communicate effectively your needs.
- Lengthy back and forth deliberation around unmet needs.
- Regional Center Staff are putting value judgments on how participants choose to have their needs met. Even though it fits wavier description.
 - Feels like they are micromanaging.
- How can DDS communicate empower Regional Centers to empower direct line staff and direct line supervisors to approve these thing as we move forward.
 - It takes a long time to get through an unmet need's discussion. If feels like there are multiple Regional Centers Delayed service, denial by delay how it feels. They will deny the service and keep you on a paper hunt with more paperwork.
- Self-Determination was intended to be Person Centered type of program, is now edging its way back to more bureaucratic Regional Center traditional way of handling an untraditional system.

Cindy Cox

- Clients at Alta Regional Center have found that your Self-Determination success is based on the service coordinator and program manager.
- Daughter was in the original Self-determination pilot program since 2001. Have see the different transitions of Selfdetermination.
- Do not think parents are getting enough information that there are transitional assistance services available to them for free to help them get their loved one through Self-Determination.
 - Parents are struggling, not knowing what to do. Unaware of transitional assistance with person center planners, and independent facilitators that can help them through that process.
- When you have a large Regional Center like Inland, want to know why they cannot transition more people. Sat in a Regional Center meeting, the Executive Director stated in the small Regional Centers have it easier. Because it is easier to move people through.

Inland Regional Center responsive to Self-Determination and are not responsive to this committee.

Marty Omoto

- That answer of regarding the difference of a larger Regional Center vs. small Regional Center was said in that way is inaccurate. That should not make a difference.
- Inland Regional Center is the largest in terms of population and area. There are some challenges, the fact is that implementation should be happening and the barriers that you are facing should not be happening.
- Change Advocacy is not about accepting or trying to find a back door to fix something temporary. Sometimes that must happen, we are going to have to work together and not except these issues.
 - We must think about the people that come after us, they should not have these still same issues.
 - We can help individuals through a barrier, but we cannot allow this to keep happening to everyone across the State the same problems over and over.

Dustlyne Beavers

- Systemic consideration is our fragile FMS system currently.
 - Lost a few FMS's now, in the past few months.
 - Challenge is how they are getting paid; how much they are getting paid. The workload and responsibility handed over.
 - Can do all the transition work and still have a significate delay.
 - As FMS's start to leave the State it is putting more burden on the existing FMS's and they are making decisions about not accepting people that are transferring from one FMS to another.
 - If we do not have the FMS structure the way the law is written, we are not going to have Self-Determination.
 - Need to stabilize the FMS structure and address the issues that are impacting them.

Christina Christenson-Rockwell

- Made noise 3-years ago when it rolled out our pilot project participants and the amount of money, we were paying the FMS and the energy that is involved with the transition and the follow-up to make sure that all the services being handled appropriately.
 - FMS put in a tremendous amount employee resources into following-up with Regional Centers to track money down. Because those systems are fragile.

Marty Omoto

- Glad you raised those issues; they were mentioned on the State level. The way all these problems are raised is that there as some
 - Immediate problems that need to be solved today or yesterday.
 - Mid-level problems that need to be solved in the coming weeks and then longer term.
- FMS issue at one point was a longer-term problem. We knew that 6-7 years ago. It is becoming increasingly more of a problem because the way the law is written. That is going to be a problem.
 - FMS's are leaving the rate of reimbursement is too low. If the budget the work needed does not match.
 - If we do not provide better direction and help what's going to happen is individuals in an FMS or company is going to start making decisions that resemble what we did not like about the continental system.
- What happens if the largest FMS in the State just pulls out?
 Does the State have a contingency to address that.
 - Many of these FMS's came in during the initial years of implementation. Serving the 2,500 it was worth getting involved. But longer term some of these FMS's are discovering that it is not worth and cannot stay in business.

Christina Christenson-Rockwell

- Currently have (4) clients that are having their transition delayed two months or longer. Because the FMS's are not prepared to bring on any more cases.
 - They are willing to work on the onboarding of the employees in the background at least the staff is ready to provide services. But you are not willing to take any new cases.
 - Long time FMS's maybe willing to take that do not have staffing starting in March. Many of the clients require someone to be on the payroll. There are very few that have not a need for paying people that are providing direct service.

Marty Omoto

 The problem is getting worse and has an impact to services. If you have an FMS that is overwhelmed because all the other FMS's have left your going to get a delay.

- Some people with FMS's is going to start saying no. To request for a family or individual. Then who do you go to say yes.
- This is an urgent problem; we must work together on how we are going to solve that problem or address it in a short-term. As well as the issue with transition and continuity of services.
- Making sure that the budget is approved, and issues individual budget are solved in a fast and timer manner.
- Person Center Change in terms of planning, the one thing to push forward is Person Center Advocacy.
 - We cannot just do advocacy that does not touch your life. That does not make a difference. It must make a difference or else it is not good advocacy.
- We are going to work together and keep each other accountable. We cannot let this happen to another family.

Legislative Report

- Kim Risser
 - SB 639 Existing law establishes a minimum wage for all industries and makes it a crime to pay and employee less than the minimum wage fixed by the Industries Welfare Commission.
 - SB 14 This bill would ensure our schools are equipped with the skills and knowledge to recognize an respond to mental health challenges and substance us experienced by students.
 - SB 281 This bill truly embodies the intension of the ADA and Olmstead Act, thus making individual choice a attainable goal in choosing housing options. This bill truly embodies the Olmstead Act, making the living in a least restrictive environment attainable goal for everyone with a disability SB 281 would assure continuation of the successful California Community Transitions Program.
 - SB 518 This bill intends to create the Cooperative for Innovation and Self-Determination (the Co-op) to serve participants in the Self-Determination Program. Program participants would be able to voluntarily opt out of being served by a regional center and become members of the Co-op. The Co-op will offer more accessible and efficient services would assure continuation of the successful California Community Transitions Program.
 - AB 313 This bill expands the State Limited Examination and Appointment Program to improve employment outcomes for people with disabilities.

- AB 323 Updates long-term care facilities citation penalties and standards for negligent care to safeguard nursing home and long-term care facility residents.
- AB 610 This bill gives school staff the choice to contact police in response to various student actions, rather than making it mandatory.

BSG/QA/CRA/VAS Projects Update

- Carol Nakamura-Robinson
 - QA Update NCI survey was supposed to start in December but is being pushed back to mid-January.
 - Reminder the NCI survey will be the Child Family Survey (CFS). Children between the ages of 0-18 who are residing with the family. Receives at least one funded Regional Center service. Will be asked to complete the Family survey.
 - Family Guardian Survey (FGS) Those are adults 18+ living in the community and receiving at least one funded Regional Center service.
 - Adult Family Survey (AFS) are adults 18+ living with their family.
 - Any of our self-advocates that receive this survey please make sure that you do participate. Because we want to make sure that all our voices are going to be heard. Not only at the State level but at the Federal Level.
- Alejandra Rivera
 - BSG Update Working on continuing trainings every month.
 This month we had (2) Emergency Disaster Preparedness Red Cross Backpack training for self-advocates. For both San Bernardino and Riverside County. There was approximately (30) participants in each training, next we will be working on providing the American Red Cross Backpacks to participants.
 - Eric Aguilar was our Presenter

Public Comments on Matters Not on the Agenda

- Alejandra Rivera
 - Regional Office has to identify an Advocacy area that in our region to work on. To develop request for proposals for a mini grant. Was asked to reach out to our Regional Advisory Committee members for input on some of these areas.
 - Looked at our data that we have from family advocates that have contacted our office. Some of the issues are Special Education primarily with litigation concerns, Self-Determination and Housing.
- Dustlyne Beavers

- SDP is my passion, but I also want to share thoughts around Special Education and the generic resources that our families keep getting referred back too.
 - Families may not have the information to navigate all the Covid-19 exceptions. Reduction in services, and what is the School District responsibility during Covid-19. Providing clarity that way families have the information to be empowered and go back to their School District and say you cannot blame Covid-19 for this, therefore you still need to be providing 1,2,3.

Ernie Saldana

- Concern is with the increase of contact with our disabled population and law enforcement. Want to continue law enforcement training to help prevent negative encounters with our population.
 - Speaking about incidents where young children are involved.
 - Corona incident that happened a couple years ago, leading to the dead of a self-advocate.
- Christina Christenson-Rockwell
 - Interested in the education, working with a couple of families being referred back to the school district for their needs to be met.
 - School Districts are falling short and limited losing staffing. Due to the recent changes with Covid-19.
 - Even with IEP in place the services that are needed are not being met because they do not have anyone to provide the service.

Alejandra Rivera

- Data from our office the previous year was litigation concerns.
 Specifically, with School District with moving forward with filing for due process.
- Christina Christenson-Rockwell
 - Part of that concern is that it is expensive.
- Alejandra Rivera
 - o Meeting on Monday to discuss this, your feedback is helpful.
- Scarlett VonThenen
 - Last RAC meeting colleague Yolanda Cruz shared that this RAC was very passionate about identifying systems issues and systemic change needs as a primary focus for the RAC.
 - Identified a number of Statewide system issues and some Regional Center issues related to Self-Determination. The Orange County was notorious for using Disencumber

Process that was not applied at any of the other 21 Regional Centers.

- Regional Center used it to reduce the individual budget.
- SCDD successful filed a 4731complaint, DDS agreed with SCDD concerns. Regional Center Orange County no longer uses that practice.
- Other Statewide system issues that are currently pending
 - Medical RX Effective January 1, 2022 will primary impact people that have very specialized healthcare needs.
 - Will affect individuals that take drugs for purposes other than the intended purpose.
 - There are individuals with significate healthcare needs, they may have epilepsy and they take a number of medications over the years and not finding one that can help mitigate seizures. So, the Doctor prescribes something off-label "off formula" in order to help.
 - Under Medical RX Doctors are no longer be able to prescribe medications other than for the intended propose.
 - This is going to negatively affect 20% of children.
 - There will be a 180-day continuity of care, so that person will still be able to take that medicine for 180-days as they go through a 60-day appeals process.
 - SCDD is actively working with DHCS to include so that Physicians have the right to prescribe medications for reason for other than the intended.
 - In August DHCS changed their notice of actions. DHCS issued notice to prioritize aid paid pending language. SCDD was successful to ask to modify the notice of action.
- Medi-Cal Historically denying speech generating and communication devices. For individuals needing an AAC device.
- Until a manager is hired for the San Bernardino Regional Office, hopefully starting January 1, 2022 there will be a new manager in place for the office.

 Until then, if you have identified additional systems concerns outside of the Self-Determination. Please send to Scarlett.

Open Discussion

- Eric Aguilar
 - Was nominated to be voted on the IEDC committee for 2022.
 Last time almost got it by three votes, but unfortunately was 3 votes short.
 - If you are interested, they are having their next zoom Inland Empire Disability Collaborative (IEDC) meeting on the December 21, 2021 from 9am-11am.
- Cindy Cox
 - Follow-up with trying to get some answers from Inland Regional Center. Is there something that we can do to get them to come and be onboard with us for our February meeting.
- Alejandra Rivera
 - Invited Don Meza one of the Directors and for the past two RAC meetings he was not available. Hopefully with the change from a Saturday to a weekday he can be available.
 - Will talk to the new manager in January and give them the information.

Meeting adjourns

- Christina Christenson-Rockwell motion to adjourn meeting.
- Meeting adjourned at 11:57am

Next Meeting

• Tuesday, February 8, 2022 from 4:00pm – 6:00pm